Title

What is ...?: a research ethics jeopardy" game to help community partners understand human subjects protections and their importance.

Journal

Progress in community health partnerships : research, education, and action, 8(3)

ISSN

1557-0541

Authors

Guerrero, Jaclyn
Madrigal, Daniel Santiago
Minkler, Meredith

Publication Date

2014

DOI

10.1353/cpr.2014.0042

Peer reviewed

What is …?: A Research Ethics Jeopardy™ Game to Help Community Partners Understand Human Subjects Protections and Their Importance

Jaclyn Guerrero, Daniel Santiago Madrigal, Meredith Minkler

Progress in Community Health Partnerships: Research, Education, and Action, Volume 8, Issue 3, Fall 2014, pp. 405-411 (Article)

Published by Johns Hopkins University Press
DOI: 10.1353/cpr.2014.0042

What is . . . ? A Research Ethics Jeopardy™ Game to Help Community Partners Understand Human Subjects Protections and Their Importance

Jaclyn Guerrero,PhD, Daniel Santiago Madrigal, PhD, Meredith Minkler, PhD

University of California at Berkeley, School of Public Health

Submitted 30 January 2013, revised 3 June 2013, accepted 23 July 2013. This work funded by NIEHS grants (P01-ES009605-13) and EPA (RD-83451301).

Abstract

Although community partners in participatory research need to understand basic principles of research ethics and human subjects protections, few tools have been designed with these partners in mind. To assist in this process, and help engage youth community partners in learning this critical material, a game was developed based on the popular television program Jeopardy(TM). Piloted with a group of 18 Mexican-American adolescents as part of a broader community-based participatory research(CBPR) project, the game begins with small group study of infamous cases of research ethics violations (eg. the Tuskegee Syphilis Study) and of the human subjects protections that resulted. The participants then play the Jeopardy game in teams, responding to "What is . . . ?" questions concerning the five infamous research studies and corresponding human subjects protections. Although observational findings revealed substantial learning and active engagement in the process, as well as strong retention of the material several months later, the tool requires further evaluation. Based on this pilot experience, however, we believe the Research Ethics Jeopardy™ Game offers promise in helping youth and other community partners in CBPR master critical information about human subjects protections and their importance in an accessible and lively manner.

Keywords

Community-based participatory research, ethics, health care, minors, community health research

One of the most challenging—and important—parts of doing community-based participatory research (CBPR) with youth and other community partners involves adequately and meaningfully engaging them in understanding and participating in processes for the protection of human subjects. Mandates requiring such protections for participants in biomedical and behavioral research were instituted in the United States based in part on recommendations put forward in the 1978 Belmont Report.[1] This report, a response to the egregious victimization of research participants in such infamous cases as the Tuskegee study of untreated syphilis in African American males[2] emphasized the importance of respect for persons, justice and other ethical principles and their applications in research involving human participants.

While time consuming and often cumbersome, [3] human subjects processes are critical, detailing how researchers, including community members of research teams, will work to insure that those who take part in a given study do so willingly with a complete and informed understanding of the nature and potential risks and benefits of their participation.

In CBPR, new tools have been designed to help researchers—and the Institutional Review Boards (IRBs) that evaluate their work—better understand and address the ethical challenges posed in this orientation to research.[4,5] With few exceptions,[4-6] however, such instruments have not been designed by or with community partners in mind—other than those who are being trained for participation as community representatives on IRBs. The dearth of such pedagogical tools is particularly problematic in CBPR and related research, in which community partners increasingly are being asked to undertake human subjects protection training (HSPT). Increasingly, community research partners must obtain

Collaborative Institutional Training Initiative (CITI) certification, developed by the National Institutes of Health (NIH) to ensure that all research partners have a clear understanding of the human subjects protections prior to their participation in such research.

We applaud the growing recognition that community-based research partners, like their academically trained researcher counterparts, should have a strong familiarity with the reasons for and content of human subjects protections. A publically available PowerPoint™ presentation for use in Human Subjects Protections Training (HSPT) with community partners was developed by Professor Eugenia Eng at the University of North Carolina, Chapel Hill and has been used both in North America and globally.[6] Similarly, many case studies and role plays have been developed to augment community partners' learning about how and why to obtain informed consent, insure confidentiality and so forth.[7,8] However, the exercises themselves tend not to be published. Finally, and while not specifically designed with community partners in mind, a comprehensive study guide now is available from the Presidential Commission for the Study of Bioethical Issues (2012). The guide looks in detail at a now much reviled study by the US Public Health Service in which several vulnerable populations in Guatemala (prisoners, soldiers, and psychiatric patients) were intentionally exposed to STDs in 1946–1948 without their knowledge or consent. The guide includes both a detailed discussion of the case and the human subjects violations involved, and numerous prompts and discussion questions for educational purposes.[9] But particularly for youth and other community partners for whom this kind of material may seem daunting, creative new tools are needed to make learning this material both engaging and more effective.

Our review of the literature and subsequent consultation with colleagues including the education director of the national IRB association, Public Responsibility in Medicine and Research (PRIM&R), however, revealed that to date, there appear to be no published accounts describing game formats used to assist in HSPT with youth and other community partners. To help address this gap, we offer a "Research Ethics Jeopardy™ Game," loosely modeled on a popular television program, in which three contestants select a question category, are given an answer and have to respond with the appropriate "What is . . . ?" question before a buzzer sounds. We begin with a brief introduction to our adaptation of the Jeopardy™ game, and describe its initial use with 18 Latino high school aged youth as part of their human subjects training and participation in an ongoing CBPR project in California. We discuss how the game was developed and piloted, and the context in which it was used. We begin with an introduction to "the basics" of human subjects material (e.g., core principles and their applications), covered primarily in a more traditional didactic format. We then present the two-part game as a supplemental tool. As noted below, we emphasized to participants that although the game format is intentionally fun and engaging, the material being covered involves serious abuses by real people who suffered as a result of their participation in the experiments described. As discussed in the Facilitator's Guide (http://www.cerch.org/ethics-jeopardy-guide), preliminary material and discussion with youth and other community partners is critical before the game is used.

Although the game was designed as a supplement to, and not a replacement for, a fuller HSPT effort, and while it has not yet been rigorously evaluated, we are hopeful that further adaptations, use and testing of this tool will increase its utility as an additional method for conveying critical human subjects material to youth and other community partners in a lively and user-friendly manner.

BEFORE THE GAME: PRELIMINARY HUMAN SUBJECTS TRAINING

Ideally, no longer than a week prior to using the Research Ethics Jeopardy™ Game**,** the facilitator should begin by offering a more didactic/dialogical presentation on the broader topic of human subjects protection. The 1978 "Belmont Report" by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research[1] is a good place to start, with participants learning that it emerged from one of the egregious studies presented in the game (the Tuskegee Study) and caused widespread outrage. The Committee that created the Belmont Report was tasked with establishing a set of rules so that subsequent research would be conducted ethically, and the kinds of abuses described in the game prevented from happening in the future. As part of their preliminary training, youth and other community members also should learn about material covered in the three parts of the Belmont Report:

The Boundary Between Practice and Research

In the Report, "practice" refers to primarily to interventions that were devised to improve individual, patient or client well-being, and that are seen as having a good chance for success. In contrast, "research" refers to an activity developed to test a hypothesis, enable conclusions to be drawn, and thus contribute to new knowledge that can be formulated as theories, principles and so forth. Typically, research is described in the form of a formal protocol including an objective and a set of processes designed to reach that objective (uiowa.edu/summary-belmont-report. uiowa.edu/summary-belmont-report).

Core Principles of Human Subjects Protection

This portion of the introductory training should include a discussion of three key principles that form the basis of human subjects protections:

Respect for persons, in this case, including in particular their freedom to choose whether or not they wish to participate in a study

Beneficence, or "do no harm," by maximizing possible benefits and minimizing any potential risks

Justice, or the fair distribution of risks and benefits in research

Application

Translating the above principles into practice in ethical research should attend to the following:

Informed consent, participants should know and understand what the research entails, its purpose, potential risks and benefits etc. prior to being asked if they wish to participate, so that they can make a truly informed decision.

Risk and benefit analysis, in the context of research, potential risks and benefits to subjects should be considered, and the risks should not outweigh the benefits

Selection of human subject, vulnerable populations, such as incarcerated people, children etc., should not be selected as subjects simply because they may be easy to recruit. Consider who stands to benefit from the research, including both individual and community benefit.[4,10]

Finally, and as noted above, prior to beginning the game, the facilitator should emphasize that despite the lively and engaging nature of the exercise, human subjects abuses, as illustrated in the particularly heinous examples they will now learn about, are no laughing matter. Indeed, it is precisely *because* of their seriousness that the game developers sought a format that would help youth and other community partners successfully master this important information.

How to Play the Research Ethics Jeopardy™ Game

The Research Ethics Jeopardy™ Game divides participants into small (4–6) person teams whose members first read about notorious cases of research violations, then plan for their participation in the game by discussing as a group their responses to questions in three key areas: 1) basic principles of research ethics, 2) how particular case studies failed to conduct ethical research, and 3) what elements (e.g., informed consent guidelines) subsequently were included in the research process to prevent those ethical violations from occurring in in future research. Participants then play the game in teams. The first team chooses a category of questions (e.g., the Tuskegee Study or Nazi War Crimes) and is asked a "What is . . . " question within that area. If their representative answers correctly, he or she picks a second question in the same or a new category. If the second question is answered incorrectly, it goes to a representative of the second team, and so forth. Points for each correct question differ by category. The team with the most points wins the round, while the team with the most points in total wins the game.

TOOL DEVELOPMENT AND PILOTING

The Research Ethics Jeopardy™ Game was initially developed by a student at the University of California, Berkeley who was undertaking an internship working with high school aged youth from farmworker families as part of the Youth Community Council (YCC) project of the larger CHAMACOS study described below. The draft tool then was then refined with the help of the Latino project director, who also served as a critical "bridge person" between the community and the university. Although local youth were not involved in the initial design of the tool, they served as participants in its piloting and their feedback, together with that of the project director and a university-based member of the research team, helped in refining the tool as discussed later.

The original Research Ethics Jeopardy™ Game was piloted in 2012 with 18 members of the CHAMACOS project's Youth Community Council (YCC) as part of a research training pro-

cess. As described more fully in the accompanying original research article in this issue, CHAMACOS is a 13-year-old longitudinal birth cohort study based in Salinas, California investigating children's environmental health (www.cerch.org). As part of the study's Community Outreach and Translation Core, high school aged YCC members learn about environmental health research and identify and study priority issues through participatory methods such as the visual, problem- posing and action process known as Photovoice.[11,12] As part of their training on research ethics, YCC members learned about and discussed research ethics requirements and their rationale, as well as participating in role plays on topics such as how to gain informed consent, and talking about the importance of maintaining participant confidentiality. The youth also dialogued about special ethical considerations inherent in visual research methods such as Photovoice, particularly in relation to respect for persons, safety and confidentiality (see Wang and Redwood-Jones, 2001).[13]

Although such background and interactive learning was useful, and did meet the requirements of our university sponsor's IRB, in retrospect, it did not provide as thorough a grounding in the rationale for and importance of human subjects' protections as we had hoped. In a subsequent "refresher" discussion of informed consent and related issues, for example, it was clear to the facilitator/project director that many of the youth had not retained some of the important "take homes" and highlights of the earlier, more didactic HSPT session. Consequently, and based on this earlier experience, the Research Ethics Jeopardy™ Game was developed and piloted with 18 YCC members. As described below, the tool consisted of two parts: a preliminary Infamous Research Study Group Activity followed by the Research Ethics Jeopardy™ Game.

Part 1: Infamous Research Study Group Activity (60 Minutes)

In the Infamous Research Study Group Activity that precedes the Jeopardy™ game, participants divide into five small groups to read and discuss one of the following short one-page summaries of 5 infamous research projects. These are:

(1) *Nazi Medical Experimentation*, in which Jewish and other concentration camp prisoners during World War II were the subjects of inhumane medical "experiments" under the guise of science.[14]

(2) *The Tuskegee Study*, in which African American sharecroppers in Alabama participated, without informed consent, in a four-decades-long study of the course and outcome of untreated syphilis. They were neither told about, nor given, a treatment for the disease for many years after one became available.[2]

(3) *The Willowbrook Experiment*, where developmentally disabled children were kept in deplorable conditions, and intentionally infected with Hepatitis to study the effects of the disease.[15]

(4) *The Stanford Prison Study*, an experiment in which college students took on the roles of prisoners and guards in a mock-prison and where the participants became overly invested in the roles.[16]

(5) *The Milgram Study*, the experiment on obedience to authority in which participants were directed to administer electric shocks to another individual.[17]

Longer summaries of these write-ups are available on line at the Youth Community Council page on the CHAMACOS website (http://cerch.org/summaries-of-ethical-research-violations).

After each of the five small groups reads their respective summary, they answer the following questions:

- Where and when did the study take place?
- What was the ethical violation?
- What has changed to prevent this violation from happening today?

Answers to each of these questions are included in the summaries provided, enabling participants to easily learn key lessons from the infamous research studies. One representative from each small group then presents the answers to the above questions to the larger group with respect to one of the five cases, thereby reinforcing the key information from each of the ethical research violations with all participants. Approximately one hour should be allowed for this part of the training.

Part 2: Research Ethics Jeopardy™ Game (30 Minutes)

Participants then are broken into new small group (4–6 members) teams to play the Research Ethics Jeopardy™ Game (see Appendix), with each team selecting a group representative. A facilitator leads the group through the game, asking five questions for each Infamous Research Project. Before each question, the facilitator tells the contestants how many points it is worth. The first team representative to raise his or her hand is allowed to respond, beginning his or her response with

the phrase "What is . . . ?" (or "Who is . . . ?") and providing the question corresponding to the statement the facilitator has provided. For example, if the facilitator says, "This is what the director of the study, Dr. Milgram, was trying to explore," the correct response would be "What is obedience to authority?" If the first team answers incorrectly, the next team's representative who raises his or her hand is given a chance to respond. Approximately 30 minutes should be allowed for playing, with the team having the most correct responses winning the game.

If possible, both the Infamous Research Study training and the Research Ethics Jeopardy™ Game should be conducted the same day, and ideally back-to-back, for maximum learning and opportunities for critical group engagement.

Piloting the Game

The 18 youth who took part in the piloting of the game participated in Part I (the Infamous Research Studies training) a full week before playing the Research Ethics Jeopardy™, which is not ideal for maximum retention of the material covered. However, both the game facilitator and the project director serving as an independent observer noted that the YCC youth did appear to collaborate effectively within their teams and correctly answered most all of the questions. The game indeed turned into a heated but friendly competition between the teams, and ultimately ended in a tie. The youth left the session still engaged in a friendly argument about which team should have won. The competitive nature of the game seemed to aid in the retention of facts, and in a YCC session months later, many of the participants were still able to recall the ethical violations of the Infamous Research Studies.

Unfortunately, no pre-game or post-game testing took place to more accurately measure youth learning. Despite this weakness, however, direct observation by the facilitator and an additional investigator, together with follow up feedback from the youth participants, suggested that the game appeared to have been successful in reaching its overall objective.

When asked retrospectively asked about their reactions to the Research Ethics Jeopardy™ Game, student responses included "lots of competition, which helped learning," "improve[d] team work skills," and "lots of fun." Others commented that taking notes on the case study for which their group was responsible helped in retention of the material, and that the time pressure of the game itself helped them focus more effectively. Additionally, when asked what about the game worked well, the youth responded that good planning helped facilitate the flow of the activity, and that splitting into different groups enabled an active approach that was helpful for comprehending the ethical violations highlighted in the studies. Others noted, however, that the game rules were not entirely clear, and should be made more explicit if the game were used again.

Youth participants also suggested that having time in the small groups to quiz each other prior to the actual game would have helped even further with their learning and retention. Several youth also suggested that in the future, each small group be given all five Infamous Study summaries, as well as the collective notes taken by each of the small groups, so that they could read them on their own and further discuss, possibly during a third session, their reactions to and reflections on the other Infamous Cases that had not been the focus of their particular small group. Finally, and perhaps most tellingly, a number of youth participants in this pilot asked if they could again play the game prior to their next participatory research activity.

DISCUSSION AND LESSONS LEARNED

Although still in need of rigorous testing, the Research Ethics Jeopardy™ may hold promise as an engaging supplement to more traditional HSPT with youth and other community partners. The short time frame needed for this activity (90 minutes total) is advantageous for workshops, class sessions and other venues in which time is an issue. As noted above, the competitive and lively nature of the game may make it particularly engaging for youth. Positive feedback from youth participants, including their desire to spend more time studying all five cases, and to repeat the game prior to their next research activity, also was encouraging.

At the same time, several disadvantages of the Research Ethics Jeopardy™ Game should be underscored. Most importantly, it does not include the full scope of HSPT, but rather focuses on five particularly egregious historical cases of research ethics violation. As such, the game in its present form should be used solely as a supplement to a broader and more traditional discussion of human subjects principles and their applications, as well as their historical grounding. Further, as noted above, the very use of the term "game" when learning about ethical violations may inadvertently downplay the seriousness of subject matter. We therefore recommend

including, prior to use of the game, a strong message that the use of this format to increase active learning should in no way minimize the seriousness of the violations discussed.

Finally, adaptations and refinements of the game should include discussion of the fact that despite the emphasis in the United States and many other countries on HSPT and research certification requirements, ethical abuses continue to occur. Newer examples might include the collecting of blood samples from members of the Havasupai Indian tribe in 1990, who had agreed to participate in a study of possible genetic components of their very high rates of diabetes. When these blood samples were then shared with other researchers, without the participants' consent, for the study of conditions including schizophrenia, tribal members were understandably upset.[18] A lawsuit followed, with $700,000 provided to the 41 participants directly affected and the Havasupai tribe's agreement to ask other tribes in Arizona to repeal resolutions declaring their unwillingness to take part in any research with Arizona State University. It should be noted, however, that the long history of abuse of Native Americans in research, together with such recent examples as the Havasupai tribe's experience, have resulted in many tribes setting up their own IRBs, with the Navajo Nation even publishing its protocol on research policies and protocols.[5]

As noted above, the Research Ethics Jeopardy™ Game is one more tool that we hope may be useful in the continuing efforts to improve HSPT, in this case, particularly for youth and other community partners engaged in CBPR. We invite readers to adapt, refine and test their own versions of the game, and, in the spirit of participatory and engaged scholarship, to share findings so that others may learn as we collectively work to improve HSPT for new partners without traditional university-based training in this important area.

CONCLUSION

The Research Ethics Jeopardy™ Game awaits evaluation through pre-post testing or other means beyond the observational data collected in this first application. Such testing, and the further tailoring of this tool to meet the needs of diverse community partners, should help increase its utility in taking some of the mystery out of human subjects discussions, while conveying important information on why rules regarding ethical research have been established and remain so critical today. The infamous research projects detailed in this activity are a deeply troubling part of modern history, and discussion of the origin and maintenance of these now reviled cases can help youth and other community-based research partners in understanding ethical research violations, and the high importance now placed on insuring human subjects protections. The Research Ethics Jeopardy™ Game may hold promise in being educational and engaging, while at the same time conveying the seriousness of this critical topic.

Helpful Web Sites

Facilitator's Guide for the Research Ethics Jeopardy™ Game (http://www.cerch.org/ethics-jeopardy-guide ; http://tracs.unc.edu/docs/research/AlternateResearchEthicsTrainingEnglish.pdf)

Summary of the Belmont Report (http://uiowa.edu/summary-belmont-report)

Eng E. Protecting people who participate in research (PowerPoint public version; http://tracs.unc.edu/docs/research/AlternateResearchEthicsTrainingEnglish.pdf)

Public Responsibility in Medicine and Research Home PRIM&R (http://www.primr.org)

Presidential Commission for the Study of Bioethical Issues (http://www.bioethics.gov)

ACKNOWLEDGMENTS

We would like to thank Gardenia Casillas, Kimberly Parra, and Jose Camacho, for their work with members of the Youth Community Council, and CHAMACOS P.I. Brenda Eskenazi, as well as other staff, for their support of our work. We also express deep appreciation to NIEHS (P01-ES009605-13) and EPA (RD-83451301) whose Children's Center grants provided the funding for the community-based participatory research associated with this manuscript. Thanks also are due to Rebecca Armstrong, Director of the IRB office at UC Berkeley, and Elizabeth Hurley, Education Director of Public Responsibility in Medicine and Research, for their helpful comments and suggestions, as well as Eugenia Eng for sharing her important earlier work in this area. Finally, our deepest gratitude goes to the members of the Youth Community Council, who took part in this pilot project and have a deep commitment to working towards a healthier community.

REFERENCES

1. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *Ethical principles and guidelines for the protection of human subjects of research*. Washington DC: Department of Health Education and Welfare. 1978. Available at: www.hhs.gov/ohrp/humansubjects/guidance/belmont.htm
2. Washington HA. *Medical apartheid: The dark history of medical experimentation on Black Americans from Colonial times to the present*. New York: Doubleday; 2006.
3. Brown P, Morello-Frosch R, Brody JG, et al. Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: A case study. *Environ Health*. 2010;9:39.
4. Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *J Urban Health*. 2007;84(4):478–493.
5. Becenti-Pigman B, White K, Bowman B, Palmanteer-Holder L, Duran B. Research policies, processes and protocols: The Navajo Nation Human Research Review Board. In: *In M. Minkler & N. Wallerstein (Eds.), Community Based Participatory Research For Health: From Process to Outcome*. 2nd Edition. San Francisco: Jossey-Bass; 2008:441–446.
6. Eng E. Protecting people who participate in research (PowerPoint presentation, public version). Chapel Hill, NC: University of North Carolina at Chapel Hill, School of Public Health; 2010. Available from http://tracs.unc.edu/docs/research/AlternateResearchEthicsTrainingEnglish.pdf
7. Simon C, Mosavel M. Community members as recruiters of human subjects: Ethical considerations. *Am J Bioeth*. 2010;10(3):3–11.
8. Chang C, Salvatore A, Lee P, Liu S, Minkler M. Popular education, participatory research, and community organizing with immigrant restaurant workers in San Francisco's Chinatown: A case study. In: Minkler M, ed. *Community Organizing and Community Building for Health and Welfare*. 3rd ed. Piscataway, NJ: Rutgers University Press; 2012.
9. Anon. *A study guide to "ethically impossible" STD research in Guatemala from 1946-1948*. Washington DC: Presidential Commission for the Study of Bioethical Issues; 2011. Available from http://bioethics.gov/sites/default/files/StudyGuide_EthicallyImpossible_508_Nov26.pdf
10. Anon. Summary of the Belmont Report. *University of Iowa, Human Subjects Office*. Available at: uiowa.edu/summary-belmont-report.
11. Wang CC, Morrel-Samuels S, Hutchison PM, Bell L, Pestronk RM. Flint Photovoice: Community building among youths, adults, and policymakers. *Am J Public Health*. 2004;94(6):911–913.
12. Catalani C, Minkler M. Photovoice: A review of the literature in health and public health. *Health Educ Behav*. 2010;37(3):424–451.
13. Wang CC, Redwood-Jones YA. Photovoice ethics: Perspectives from Flint Photovoice. *Health Educ Behav*. 2001;28(5):560–572.
14. Jotkowitz A. The Holocaust and medical ethics: The voices of the victims. *J Med Ethics*. 2008;34(12):869–870.
15. Krugman S. The Willowbrook hepatitis studies revisited: Ethical aspects. *Rev Infect Dis*. 1986;8(1).
16. Zimbardo PG. Revisiting the Stanford Prison Experiment: A lesson in the power of situation. *Chron High Educ*. 2007;53(30).
17. Russell NJC. Milgram's Obedience to Authority experiments: Origins and early evolution. *Br J Soc Psychol*. 2011; 50(Pt 1):140–162.
18. Mello MM, Wolf LE. The Havasupai Indian tribe case—Lessons for research involving stored biologic samples. *N. Engl. J. Med*. 2010;363(3):204–207.